



Autism Spectrum Disorders

About this booklet

Do you know someone who has an autism spectrum disorder? Chances are, you do. Responding to many requests from Missourians for information about autism, this booklet reflects a careful review of the latest autism research, and provides resources.

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—**Kristen Heitkamp, Editor**
April, 2005

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Preface

by Geoff Lanham, Project LIFE Coordinator

The diagnosis didn't match the behavior.

For a long time, I knew in my head and in my heart that there was something different about my youngest son, Grant. While the symptoms of ADHD were present, there were other behaviors that often alarmed me.

Grant started reading at the age of three. He was fascinated with dinosaurs and could tell you all about the diplodocus and triceratops. Grant often asked me for definitions of words that I had to look up in the dictionary. He was able to compute math problems that most six-year-old children couldn't touch. Grant's teachers complimented him on his intelligence.

His conduct at home wasn't really worrisome. Grant never got into much trouble. Although he always needed prompting to eat or to bathe, or to do common household chores, he wasn't much different than my other children. Then why was there a problem?

At first I thought it was the divorce and new home—changes that would account for any six-year-old child's behavioral problems. We also changed Grant's ADHD medication—that in itself was a living hell. When the dust settled from the divorce and the move, however, he was still acting out at school. On occasion, Grant had trouble with adults, but most of the aggression was directed at his classmates. This behavior was unacceptable—to me and to his teachers.

When Grant was suspended from school for a lunchroom incident, I had the opportunity to discuss his problems with the vice-principal. After a long talk, we agreed that he needed further psychological testing. She recommended referral to the public school autism specialist. Once again, we faced the arduous task of filling out paperwork. Both his mother and I answered questionnaires. For over two hours, we both were questioned by the autism specialist. His teachers were questioned. No stone was left unturned.

Finally the day arrived. We found out why Grant behaved the way he did: he was diagnosed with Asperger syndrome (AS). Having read about this disorder (when my nephew was diagnosed with autism), I recognized many of the characteristics in my son. Back then, I hated to put another label on Grant, and discarded the notion that he might have autism. Now I know better.

Although Grant has another label attached to his resume, this one has been a relief. With insight into Asperger syndrome, we can help my son by anticipating problematic situations. Grant's troubles seemed to happen in very noisy circumstances (in the gym or during recess), places where the decibel level makes the hardest of hearing plug their ears. The lunchroom was always difficult. Not only was noise bothersome, but certain smells also set him off. Grant would push or shove or throw things at fellow students. When I asked him why he did these things, Grant just said, "I don't know Dad, I really don't know."

Now I know, and it's getting easier to adapt his environment or to anticipate a challenge. For instance, children with AS are very sensitive to sound. Grant will cover his ears and get in the fetal position if a fire engine is within a couple of blocks—even when I can barely hear the fire engine. I cannot run the vacuum cleaner when Grant is in the house, because he acts as if someone is running fingers on a chalkboard, and he screams as if in pain.

Certain smells set him off: garlic, for instance. Grant eats only particular foods. I've learned to choose my battles, and as long as Grant is eating, it's better than fixing a meal that will sit on the dinner table, get cold and end up in the garbage.

I play a game with him called "let's see who can stare the other down the longest." Children with AS have a difficult time maintaining eye contact; their eyes wander back and forth. With a lot of effort—the "stare down" game—we are making progress.

Children with AS often take things literally. If you say it is "raining cats and dogs", don't be surprised if a child looks at you in a puzzled manner. To him, it is just raining; there are no cats and dogs falling from the sky!

At school, we've adapted Grant's routine. For instance, he has lunch in the assistant principal's office. He has one recess instead of two. He is given advance warning of a fire drill. These simple steps improve Grant's ability to get along with his peers.

As parents, we need to follow our instincts. We know what makes our children tick. I know that my son will struggle in the classroom. I know that he will shine, as well. Grant has been fortunate. His teachers perceived his strengths, and always encouraged him to be the best student possible. They knew in their hearts and minds that something was different about him. Together, we finally figured it out.

Introduction

Imagine, if you will, waking up one day. Your bed, your arms on the sheet, the book on the table, are seen in fragments. You try to focus but cannot. Lights flash off and on. Everything in the room seems to have a hard edge, without shades of gray, as if you woke up inside of a video game.

And the noise! BOOM boom BOOM boom BOOM boom. It could be the beating of your heart, footsteps in the hall—you have no idea.

Your arms feel asleep. You raise a hand and consider it, shaking it once to see what it will do. Lying back on the pillow, you hear another sound and freeze in fear. Something is touching you, a figure with darting eyes, making unrecognizable sounds. The figure grabs your hand—you scream, close your eyes and cover your ears, willing it to go away.

Imagine waking up with autism.

What is Autism?

Autism, or autism spectrum disorders (ASD), comprise a variety of developmental disorders related to

- communication
- developmental delays, or uneven development
- sensorimotor functions, and
- social interaction

Autism represents a wide range of cognitive and physical abilities, which vary considerably among diagnoses and individuals—thus the designation as a “spectrum.” Because of this variability, diagnosis of autism is confusing. For instance, a person, who has a normal to high IQ and the ability to communicate, may be diagnosed with either Asperger syndrome, Asperger Disorder or High Functioning Autism. All of these labels describe the same set of symptoms.

Autism spectrum disorders involve biological systems: the brain, the immune system, the sensory/nervous systems and the gastrointestinal system.

Individuals with autism may have other (co-occurring) disorders such as seizures, allergies, gastrointestinal disorders, sensory disorders, hyperactivity, and anxiety or mood disorders.

NOTE:

In most cases, the words “autism” and “autism spectrum disorder” are used interchangeably.

“As a parent, what is not important is the label, but how I can help my child.”

— Betty Kramer, RN

REFERENCE

William Barbaresi, et. al.
in *Archives of Pediatrics*
and Adolescent Medicine
(1/05), on-line at:
[http://www.mayoclinic.org/](http://www.mayoclinic.org/news2005-rst/2551.html)
[news2005-rst/2551.html](http://www.mayoclinic.org/news2005-rst/2551.html)

Researchers say autism spectrum disorders are a result of a combination of perhaps 10 to 20 genes, plus environmental factors, that seem to cause the brain to exhibit less activity in its social and emotional centers. (*New York Times*)

Prevalence

The reported prevalence of autism varies—the National Alliance for Autism Research estimates one in every 250 births, while recent studies place the prevalence as high as one in every 166 children.

Some scientists caution that the apparent rise in autism spectrum disorders may be due to increased awareness and diagnosis of these disorders.

Reviewing an epidemiological database in Olmstead County, Minn., Mayo Clinic researchers found that the incidence of reported cases of autism was stable prior to 1988. When diagnostic criteria for autism expanded in 1987, and new federal special education laws included autism as a disability category, the rate of reported autism increased.

Authors of the study theorize that, prior to these changes, children with autism may have been diagnosed with “developmental delay” or “mental retardation,” while children with milder symptoms of autism may not have been identified at all.

What causes autism?

Researchers have identified a genetic predisposition to autism spectrum disorders, which “interacts with an as-yet-unknown environmental factor or factors and causes alterations to the immune system, the sensory nervous system, the brain and often the gastrointestinal tract as well.” (Cure Autism Now)

Recent research at Johns Hopkins School of Medicine suggests that autism may be related to brain inflammation, and further, the brain’s immune system may be triggered by factors “possibly including birth complications, diet, toxins or infections.” Researcher Carlos Pardo summarized: “These findings reinforce the theory that immune activation in the brain is involved in autism, although it is not yet clear whether it is destructive or beneficial, or both, to the developing brain.” (*Annals of Neurology* 57, 1 (2004)) A BBC report on this study adds that “another [study] found raised levels of nitric oxide in the plasma of children with autism. This chemical plays a role in the immune response, and is known to affect neurodevelopmental processes.” (Nov. 15, 2004)

While both genetic and environmental factors are responsible for autism, there is no single cause. Theories that vaccines cause autism are unproven. (See related information on p. 21.)

Sensorimotor Symptoms

Auditory Deficits

Individuals with autism often have difficulty processing auditory information. Some individuals may be overstimulated because they are unable to discriminate between sounds, or they are unable to filter out background noise. Some individuals are highly sensitive to different sound frequencies, while others may be sensitive to loud noise.

CAPD

Some individuals exhibit symptoms of central auditory processing disorder (CAPD), a hearing impairment located in the brain (where incoming speech is “processed” and understood) rather than in the ear.

Internal symptoms of CAPD:

- difficulty discriminating foreground from background noise
- distortions of incoming speech
- delay or “lag time” in processing speech

External symptoms of CAPD:

- asking for repetition (“huh?” “what?”)
- echolalia
- articulation difficulties
- responding incorrectly to spoken directions (for instance, processing “incomplete sentences” for “*in* complete sentences”)
- apparently “ignoring” people
- interrupting or “speaking over” people
- delayed response to speech

(from <http://www.autistics.org/library/capd.html>)

Speech and Language Deficits

Some individuals with autism hear the spoken word as a meaningless sound. As Temple Grandin writes, they do not perceive language as a way of communicating. Many of these individuals, who may be visually oriented, learn to talk when the sound is associated with a picture or the written word. Some people communicate through singing, and singing may become a “bridge” to the spoken word. Often children will echo what they hear (echolalia) or have heard (delayed echolalia). (Grandin, *Thinking in Pictures*)

REFERENCE

Stephen M. Edelson, Ph.D.,
“Auditory Processing
Problems in Autism.”
Center for the Study of
Autism. (Salem, Oregon)

Speech and language deficits, continued.

Testing by an audiologist can determine how well a person can hear a range of frequencies in each ear. From there, speech and language therapy, designed for individual needs, is essential. A certified speech pathologist can assess and design specific interventions to improve language comprehension and skills.

Visual Deficits

Many people with autism report visual perceptual problems, such as tunnel vision, reliance on peripheral vision, or difficulty in telling foreground from background. Other problems may include:

- sensitivity to light frequencies, typically to fluorescent light which flickers and emits a high buzzing sound;
- inability to focus on constantly changing visual stimulation, such as another person's eyes;
- visual “overload” producing sensations such as strobing, white light;
- difficulty with multisensory processing: inability to look at someone and listen to them at the same time.

An optometrist can rule out other problems with a visual exam.

Some of the areas in which individuals have visual differences may also provide their strengths—seeing differently can be an asset to an artist, for instance.

Hypersensitivity to Smell

Because of hypersensitivity to smell, some children with autism may refuse to eat certain foods, go to a zoo, sit in the school cafeteria, or visit a farm. Household chemicals, laundry detergent, perfume, cigarette smoke or cooking odors may trigger sensitivities.

Food Allergies

The rate of both food allergies and food sensitivities among people with ASD appears to be higher than the 5% norm. Common causes of food allergy are milk, eggs, peanuts, soy, nuts, fish and shellfish. Food allergies are confirmed by a skin-prick or blood test. Besides allergy testing, a child may be tested for vitamin or metabolic deficiencies with a urine test. (See “Dietary and Biomedical Treatments,” page 15.)

REFERENCE

Luke Jackson, *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*. (2002) Jessica Kingsley Publishers: London.

Touch and Tactile Sensitivity

One of the early signs of autism is observed in babies who scream when they are touched or hugged. Some people with autism report that light touch can be painful, or may incite feelings of anxiety. (For instance, imagine when your leg has “gone to sleep” and you feel “pins and needles.”)

Luke Jackson writes that clothing can feel especially torturous, especially clothing labels, new jeans, scratchy fabric or wool socks. Well-washed, soft, natural fabrics such as cotton and silk are preferable.

Others report that they have little or no sense of their bodies; some do not feel “in” their bodies, or perceive an arm or leg as a part of their body. Some self-stimulating behaviors are related to these feelings: hand flapping or wringing, twirling or rocking.

For many people with autism, a light level of tactile stimulation is painful; they actually crave *deep* pressure (received by bumping into walls, or rolling, or hitting their arms or leg).

A typical day ...

Educational Consultant Alex Michaels, who has Asperger syndrome, describes a typical school day:

All of a sudden my ears felt as if someone was taking a rototiller and cutting up my eardrums—the lunch bell rang. Next, I needed to claw my way into the jungle of smells where my classmates corralled around the coat hooks grabbing their lunch bags ... as I descended into the cafeteria of despair, I would do battle on the stairs as the sour smell of linoleum lined my nostrils...As if that wasn't bad enough, this overstimulating environment only led to the torture chamber (AKA: playground) where each day I was reminded of just how much I didn't fit in.

Assessment

Red Flags

“Red flags” may indicate a child is at risk for developmental disorders, and should have an **immediate** evaluation. If your child shows any of the following signs, don’t hesitate to call your doctor:

- No big smiles or other warm, joyful expressions by **6 months** or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expressions by **9 months** or thereafter
- No babbling by **12 months**
- No back-and-forth gestures, such as pointing, showing, reaching or waving by **12 months**
- No words by **16 months**
- No pretend play by **18 months**
- No two-word meaningful phrases (without imitating or repeating) by **24 months**
- **At any age**, ANY loss of speech or babbling, or of motor skills
- **Acute** sensitivity to touch, taste, noise or smells
- Repetitive behaviors like hand wringing, head banging, twirling
- Odd use of the eyes

REFERENCES

Greenspan, S.I. (1999)
Building Healthy Minds,
Perseus Books: New York.

Filipek, P.A. et al. “Practice
parameter: Screening and
Diagnosis of autism.”
Neurology 2000, 55: 468-79.

Assessment/Diagnosis

An assessment of autism is based on observation of a child in various settings: the home, school and clinic or doctor’s office. The diagnostic evaluation of autism will often include a complete physical and neurologic examination and use of specific diagnostic instruments such as the Childhood Autism Rating Scale (CARS); and Autism Diagnostic Observation Schedule (ADOS).

It is important that the interview include an in-depth social history with the parents or caregivers, and with others who know the child well. The interview may include assessment using one or more rating scales. The ADOS, a structured interaction with the child, is considered the gold standard in autism diagnosis.

For high functioning individuals, instruments specific to this population are the Asperger Syndrome Diagnostic Scale and the Gilliam Asperger Diagnostic Scale.

Interventions

Autism Toolbox

Think of interventions as tools. You wouldn't have just one tool, would you? "If you only have a hammer, then everything looks like a nail."

— Julie Donnelly

Typically an intervention team includes parents, a trained consultant, speech pathologist, occupational therapist and special educators.

Typically, childhood development is an orderly process of acquiring and building upon skills. In ASD, however, the brain is unable to interpret sensory information, and to develop appropriate neurological responses. Therapy is designed as an intervention that retrains the brain's neurological functions.

Treatment plans are based on a child's symptoms and the level of neurological impairment, and are designed to address the individual's needs. A National Academy of Sciences report (2001) suggests at least 25 hours a week of intensive training, starting with a child as young as age two. Other researchers noted, "fragmented, weak efforts in early intervention are not likely to succeed, whereas intensive, high-quality, ecologically pervasive interventions can and do." (*American Psychologist*, 1998)

Therapy includes the following components:

- Speech and language therapy, in order to address language and communication delay
- Occupational therapy to improve sensory integration and motor skills
- Visual supports
- Social skills training
- Highly structured, one-to-one, and small-group education

Complementary therapies include hippotherapy, music therapy, and auditory intervention training, page 13. Educational interventions are discussed in "Case Studies," page 17.

Behavioral Interventions

Behavioral techniques help children with autism develop communication and social skills. Three strategies define the interventions: behavioral management using rewards and consequences (a star chart, for instance); functional behavioral analysis, in which the motive for a particular behavior is assessed (Why does he have his hands over his ears? Is he hypersensitive to noise?); and positive behavioral support (such as social skills building).

Parents learn behavioral techniques in order to provide structure in the child's environment, provide consistent rewards, and set limits.

Various intervention programs are designed specifically to enhance communication and cognitive skills. No single method works for all children; analysis of the research shows that approximately half of the children improve with any type of intervention. Rarely do individuals “recover.”

Any intervention strategy should be designed to accommodate the strengths, interests and needs of the individual. Specific intervention programs or techniques include:

- Applied behavior analysis such as discrete trial-based training (Lovaas-type). This type of intervention is based on helping a child with ASD react to stimuli from the environment. In discrete trial-based training, a child is prompted and rewarded for a correct response.
- “Developmental/Individual Difference Model” is based on an analysis of where in the normal sequence of development the individual child went off the track, and on crafting a strategy for getting development back on track. It is designed to accommodate individual needs within unique family and cultural patterns.
- Building on the “individual difference” model, Dr. Stanley Greenspan developed a concept called “Floor Time,” in which the caregivers (generally the parents) join the child in his or her preferred activity (with the intent of developing this action into an interaction). The caregiver must be able to identify an opportunity to teach a particular skill (such as taking turns), and then repeat the “lesson” until the child has acquired the skill.
- “Social Story” technique is used to teach better understanding of the many social and behavior concepts and routines that are a part of human relationships. Often individuals with autism “misbehave” because they don’t understand implicit or nonverbal social rules. Through a social story, written specifically for that child and that situation, the therapist or parent shares the social cues that the child misses. The story helps the child understand the expectations and feelings of others in the situation, and gives cues to help the child choose socially appropriate behaviors. Social Stories can be written for all levels of functioning, by using pictures and varying the level of the language.

RESOURCE

**[www.thegraycenter.org/
Social_Stories.htm](http://www.thegraycenter.org/Social_Stories.htm)**

Complementary Therapies

Often, children with autism learn a social skill or routine within a particular setting, but cannot apply the lessons to everyday life (generalize). Complementary therapies help children use classroom skills in the real world.

Therapeutic Horseback Riding (Hippotherapy)

Hippotherapy literally means “treatment with the help of the horse” from the Greek word, “hippos” meaning horse.

— American Hippotherapy Association

Therapeutic riding (hippotherapy) promotes sensory integration, coordination, balance and communication. The physical benefits are based primarily on the movements of the horse, which helps to improve the rider’s balance, coordination, strength and muscle tone by gently mobilizing the rider’s joints.

For those with ASD, horseback riding offers additional benefits, as one mother notes: “Things like listening skills, awareness of things around them, skills with animals, friendships they can’t get in the schools, learning the days of the week so they know which day they ride, responsibility...” The many aspects of hippotherapy (riding, grooming, bonding with the horse) encourage effort, develop a positive attitude, and promote a sense of well-being and accomplishment.

Auditory Intervention Training Strategies

Why do some children with autism hold their hands over their ears? They are hypersensitive to sound, or they cannot filter out background noise. Temple Grandin writes that unexpected noise, such as a public address system in schools, can be so frightening that a child will refuse to return to the classroom.

In 1950, the French physician Alfred Tomatis noted that the brain responds to “sound overload” through a process of blocking a particular frequency, or by “shutting down.” He developed an instrument (“Electronic ear”) that modulates—or changes—sound that enters the ears. Other sound therapies bear similarities to this method, such as Berard Auditory Integration Training, or Samonas Sound Therapy. While these approaches may help some people, they have not been verified by research studies to help all.

RESOURCE

To find a therapeutic riding center near you, contact North American Riding for the Handicapped Association (NARHA) at 800-369-RIDE (7433) or on-line at www.narha.org

Music Therapy

Along with other learning strategies, music therapy can provide physical and emotional outlets:

Music provides concrete, multisensory stimulation (auditory, visual, and tactile). The rhythmic component of music is very organizing for the sensory systems of individuals diagnosed with autism. As a result, auditory processing and other sensory-motor, perceptual/motor, gross and fine motor skills can be enhanced.

—American Music Therapy Association

Touch

People who have autism may be hypersensitive to light touch, but deep touch may feel good. As part of sensory integration therapy, the “Squeeze Machine” (invented by Temple Grandin) allows a person to apply constant, deep pressure to the body; Grandin reports that this is comforting and calming. Grandin also suggests using a “mummy” type bag to sleep in. Some kids like to have rubber bands or snug shirt cuffs.

Recreation Therapy

Children who have autism spectrum disorders vary in their abilities and interests, but all have a need to relax and enjoy life. Acquiring leisure interests and skills is just as important as learning math or making a sandwich. Recreation therapists are trained to assess leisure interests and adapt recreation programs to the needs of the participants. Strategies may include direct instruction, peer mentors, and the selection of programs with an appropriate level of inclusion and support.

When you’re exploring recreation opportunities for your child, the recreation staff should be able to

- offer suggestions for leisure interests;
- assess your child’s ability to participate in a program; and
- adapt a program to the needs of your child.

The Americans with Disabilities Act (ADA) mandates that no child can be excluded from a community recreation program on the basis of disability. In the past, many recreation departments have adapted a “continuum of leisure options” (Schleien, et al.) ranging from “segregated” programs like “Special Olympics” to “integrated” (or mainstreamed) programs.

RESOURCE

**National Center on
Accessibility**

(812) 856-4422 (voice)

(812) 856-4421 (tty)

(812) 856-4480 (fax)

nca@indiana.edu

website: www.ncaonline.org

Medications

While there is no “medication” for autism, there are medications that address some symptoms: for hyperactivity, depression, seizures, obsessive compulsive symptoms, aggression or anxiety. Sometimes medications are prescribed that do not seem to be appropriate, but actually work. For instance, some individuals without seizures often respond well to seizure medications. Every child is different.

The doctor looks at the symptoms and then tries medication for particular symptoms. Since each drug works differently in each body, often you may have to adjust medication levels.

You must see a medical doctor to decide which medications are necessary. It's important to find a physician who is experienced in prescribing medication for autism, and to maintain an ongoing relationship with the physician. If a medication is not working, it's important to get in touch with your doctor, and get good advice on changing meds. Be prepared to try several different medications or drug combinations until you find what is right for your child. Finally, realize that your child's needs will change over time.

—Julie Donnelly, Ph.D.

Dietary and Biomedical Treatments

The following treatments have been reported to alleviate some problem behaviors, and in many cases, help children feel much better. While the anecdotal reports and case studies are compelling, few controlled scientific studies have consistently replicated results.

- Gluten Free/Casein Free (GFCF) diets address allergies to gluten, (found in wheat, oats, rye and barley); and casein (from dairy products).

- An anti-yeast (fungal) diet addresses yeast intolerance.

- Mercury detoxification (chelation) may be recommended for those who have been exposed to high levels of mercury, or who are very sensitive to mercury.

- Dietary supplements such as Vitamin B6, magnesium and essential fatty acids may be helpful. Consult your physician before taking a supplement.

- Studies reported by the National Institute of Health indicate that the hormone secretin is no more effective than taking a placebo.

REFERENCES

Cure Autism Now!

www.cureautismnow.org

Web site list of metabolic research studies:

www.panix.com/~donwiss/reichelt.html

Also see www.gfcfdiet.com/Explanationofdiet.htm

Educational Interventions

Autism spectrum disorders are medical diagnoses. The public schools also evaluate students for “educational autism.” While the educational and medical definitions are similar, the assessment procedures are different for each. To receive special education services, your child must go through the educational evaluation process.

IDEA

The federal Individuals with Disabilities Education Act (IDEA) provides that every child with a disability under the age of 21 is entitled to a free, appropriate public education. IDEA mandates that all children should receive their education in the least restrictive environment. Although the law encourages placement in neighborhood schools and interaction with typical peers, the child’s needs determine actual placement.

Depending on the child’s age, an Individualized Family Service Plan (IFSP; for children under 3) or an Individualized Educational Program (IEP; for students 3-21) describes the special educational and related services specifically designed to meet the child’s needs.

The student must be assessed and found eligible for services. This evaluation also provides information on current functioning, which is used to write the Individualized Education Plan (IEP).

Following the assessment, an IEP is developed. Members of the IEP team include the child’s family and the child (especially after age 14); special education professionals; the Local Educational Authority (LEA)—the school principal, counselor or special ed administrator who has the authority to delegate resources; and a regular education teacher. The parents may invite their physician or personnel from other support agencies, but these are not required.

Parental rights under IDEA include:

- The right to be informed about any evaluation activities that will be conducted with their child;
- The right to attend the IEP meeting and have input into the formulation of the IEP;
- The right to contest an IEP recommended by their local district if they do not feel it meets their child’s needs;
- The right to a hearing and to mediation to resolve such conflicts;
- As a last resort, the right to take the school district to court to resolve their differences.

RESOURCE

To learn more about IDEA and federal programs for special education, see the Office of Special Education Programs (OSEP) web site at www.ed.gov/about/offices/list/osers/osep/index.html

Preschoolers

Services for children under three are usually home-based, with professionals visiting periodically to evaluate progress, provide direct teaching, and recommend activities to parents. Children from age three to five may be served in special programs, or in typical preschools with supportive services.

Case Studies

by Julie A. Donnelly, Ph.D.

Co-occurring condition: may include sensory deficits such as poor eyesight or hearing; medical conditions such as allergies; or psychiatric disorders such as ADHD.

“Receptive” language: learning to listen and understand spoken language; skills focus on auditory memory, following directions, and concept development.

AS A PARENT, I saw my son develop from a child with symptoms of classic autism to an adult with Asperger-type differences.

But nothing prepared me for the diversity of autism present in the public schools, where there is a range of desire and ability to communicate among individuals, and a variety of communication systems they may rely on. Sensory differences may cause these children to pull back from interaction, and to have unusual behaviors. Often their lives are complicated by co-occurring conditions. Add individual personalities, family experiences, education or therapy environments, and it comes as no surprise that these children are as different as snowflakes.

The following stories illustrate the range of educational needs for individuals on the autism spectrum.

COREY is a three-year-old with very limited communication skills. He signs the word *eat*, but uses it to mean many different things. Corey’s play is best described as sensory-based. He likes to throw toys, run his hands through sand, and to “wave” items, in order to look at them out of the corner of his eyes. It is difficult to get Corey’s attention and, when engaged, he remains focused for only a few seconds. Corey often runs off, and has to be watched closely. Some say he is “noncompliant,” but since Corey does not understand much language, his lack of compliance is likely due to receptive language difficulty.

Corey is not yet toilet-trained, eats with his fingers, and can dress only with direction and assistance. While he seems comfortable in the company of familiar adults, Corey doesn’t yet recognize individuals beyond his mother. He shows no awareness of peers.

Corey is enrolled in an intensive early-childhood special education program. Designed for his unique personality, the program helps Corey to feel comfortable and safe in the school setting, and to build relationships.

An integral part of Corey’s team is the Occupational Therapist (OT) who works directly with Corey, and consults with his teachers. During short periods throughout the day, teachers work with Corey on a one-to-one basis. Some of these sessions are highly structured to help Corey recognize, imitate, and understand receptive language.

In therapy, a skill is taught in a structured setting and “generalized” for a social environment.

PECS (Picture Exchange Communication System): a way of communicating with visual symbols rather than words. The symbols or pictures may be drawn or pasted on index cards, or attached to a picture board.

Pragmatic skills: using both verbal and nonverbal language to give and receive information.

Other sessions are devoted to play time, where staff members follow Corey’s lead, building interactive play routines with a variety of toys and materials. During play time, staff members work on generalizing the language and skills that Corey is learning in the more structured setting.

A speech-language therapist works one-on-one with Corey, teaching him to use the Picture Exchange Communication System (PECS). Corey has mastered the idea of the exchange (that when he hands someone a picture, he gets something he wants), but still has difficulty distinguishing one picture from another. Everyone working with Corey attempts to help him (and his mother) use the PECS system.

Depending on his ability to cope, Cory joins his peers for “open circle.” Currently he is sitting with the group for a short time during music—a preferred activity. Although Corey’s supports are intensive, he is beginning to learn the routines of his school day, and to demonstrate slow but steady progress.

AMY exhibited problem behaviors in preschool. She refused to sit and listen to stories; she played alone with specific toys; when other students “got in her space,” Amy often became aggressive.

Amy knew her ABCs and numbers better than other preschoolers, yet she refused to do work sheets or art projects. Sometimes Amy had meltdowns and screamed. Despite warnings from the preschool director, Amy’s parents hoped she would grow out of her problem behaviors. Amy did not.

When Amy entered kindergarten, the school sought an evaluation. The diagnosis of an autism spectrum disorder shocked Amy’s parents, but they agreed the characteristics fit their daughter.

In kindergarten, a language therapist sees Amy individually (to build pragmatic skills), and also in a pair or small group setting (where Amy practices social language). At other times, the language therapist observes Amy in the classroom, and offers support by prompting generalization of new skills.

A thorough evaluation by an OT uncovered sensorimotor problems. The OT provides services in the classroom environment, where the teacher created a “quiet space” for Amy to use when she feels overwhelmed and needs to relax.

While Amy displays some skill in rote memory, she has difficulty understanding instructions and completing her work. A support person (aide) helps Amy with classroom tasks and projects, and also helps Amy learn to play with a wider variety of toys, and to interact with her peers.

Expressive language: skills include using a vocabulary, and the ability to narrate, or tell a story.

An IEP (Individualized Education Plan) is reviewed and adapted on a regular basis.

Federal law mandates that students with disabilities will have a plan in place to aid in their transition from school to community.

MARY is in a fourth-grade inclusive classroom setting, where (with guidance from classroom and special education teachers) a support person adapts the regular curriculum for her. Mary participates in many classroom activities. While Mary can speak, she needs therapy to increase her receptive, expressive and pragmatic language skills. Mary has always had friends, but since she is not as emotionally mature as her classmates, Mary is often confused by some of their complex friendship rituals.

Mary's parents know that their daughter will probably need continuing special education support. Mary may not be totally mainstreamed in secondary school, given the curricular challenges at that level. However, her parents hope that Mary will be able to find employment and live in the community with a moderate level of support.

JOHN's parents were very nervous about their son's move to middle school. John had been quite successful in his elementary school setting, with some special education "pull out" and in-class services. While John communicates, he has a great deal of difficulty with social cues. In elementary school, everyone knew John—so when he said something unusual, students and teachers accepted it as part of who John is. His parents worried that students and teachers would not accept John in the middle school environment, and alerted his teachers that John might be bullied.

John also struggles with academics. While he often doesn't understand what the teachers are saying, he won't tell them so. This creates a vicious cycle, as they get upset when John doesn't turn in his work. Due to this concern, his IEP team decided that he should stay with his peers in most classes, but also spend two periods in a resource room. There, special education staff help John complete his work, and make sure that he understands the course concepts. John also is placed in a pragmatic language/social skills group.

RON spent all of his schooling in a special education "self-contained" classroom. He has basic communication skills, but cannot understand more complex language. Now 18 years old, Ron is in a "community skills" class, where he works in different community environments during the school year. The staff assesses the type of work Ron does best, and determines the amount of support he needs to complete tasks. Members of his IEP team, and some community agencies, are planning for Ron's transition when he turns 21.

**504 Plan:
a program of instructional
services to assist students
with special needs who
are placed in a regular
education setting.**

When he is not in a work setting, Ron attends the local high school, where he is friendly, and well-known for his special interest in fly swatters. In fact, both students and teachers have given Ron special fly swatters, and regularly ask him about his unique collection.

HARRY, a young man with Asperger syndrome, is graduating from high school with honors. Given the challenges of AS, Harry's success surprises and pleases everyone. In the last few years, Harry has needed only a 504 plan. This federally-mandated plan is used for students whose difficulties are in the mild range. In Harry's case, only a few accommodations are needed, such as preferential seating and extended time on tests. Harry is well aware of his differences, and sees a counselor regularly. He has two good friends who like and accept him for who he is.

Harry looks forward to going to college, where his serious attitude and excellent reading ability should help him to succeed. Harry's counselor has not only helped him to better understand his Asperger's differences, but also has introduced Harry to an Internet group of others with similar characteristics and traits.

Students receiving services for autism are as diverse as the interventions they receive, and it's apparent that a diverse group of caregivers delivers these services. Keep in mind that the best services help students attain not only success, but also independence.

It is important to understand that autism is a multicausal phenomenon. There will not be one cure found, but we are finding some pieces of the puzzle. I do not know of miraculous recoveries. In fact, my son would be offended at the thought. He says he is not a failed or broken normal person, he is a perfectly fine person with autism. And he and the other individuals on the autism spectrum have a lot to contribute to this world.

[Julie Donnelly, Ph.D. has over 24 years of teaching and school consulting experience with all ages and disabilities, specializing in teaching students with autism. She is recognized nationally as an authority on autism. Her son Jean-Paul Bovee is a well-known speaker and person with autism.]

See Dr. Donnelly's website at www.autismsupports.com.

Psychiatric Diagnoses

In order to qualify for medical or insurance services, parents of children with autism spectrum disorders seek professional psychiatric diagnoses. These diagnoses are based on criteria from either the International Classification of Diseases (ICD-10) or the American Psychiatric Association *Diagnostic and Statistical Manual IV* (DSM-IV). Note that psychiatric diagnoses on the following pages are based on DSM-IV criteria.

In addition to the medical diagnosis, a child must be assessed in the educational system, in order to receive special education services. The two sets of diagnostic criteria do not necessarily correlate: a child may be diagnosed with High Functioning Autism as well as Asperger Disorder, or with PDD-NOS as well as Autism.

The inconsistency is due, in part, to the variability of behaviors in the autism spectrum disorder.

While scientists have attempted to diagnose autism based on behavioral characteristics, Dr. Judith Miles at the University of Missouri Autism Project clinic researched a different approach, “separating children who experienced central nervous system insult during [fetal development] from those who did not.” In a study of 465 patients admitted to the clinic, Dr. Miles found that approximately 30% of the group display “complex autism,” defined as autism in combination with dysmorphology, brain abnormalities, or microcephaly (small head). Children with “essential autism” were defined as those without dysmorphology, brain abnormalities or microcephaly.

REFERENCE

Miles and Fennell, “Autism and Jourbet’s Syndrome,” 2002.

*Comparison of the subgroups suggested higher IQs, fewer seizures and abnormal EEGs, a regressive pattern of onset, higher prevalence for males than females, and higher family recurrence risk for children with **essential** autism. In contrast, children with **complex** autism had lower IQs, more seizures and abnormal EEGs, a gradual onset, a more even gender distribution, poorer outcome, and a lower familial recurrence risk.* (Miles and Fennell)

In summary, different diagnoses of autism attempt to describe the extensive variants of the disorder, and over time, a child may be assessed and given a different diagnosis.

Autistic Disorder (classical autism, Kanner's syndrome)

**syndrome:
a group of symptoms
indicating a biological
condition**

First described in medical literature by Leo Kanner in 1943, autism is a syndrome that includes some element of at least three criteria.

- Some qualitative impairment in reciprocal social interaction. This may be characterized by poor use of eye gaze and gestures, and a lack of interest in (or ability to develop) personal relationships.
- An impairment of communication—verbal and nonverbal—characterized by a delay in language acquisition, lack of (or poor) speech, lack of spontaneous play.
- A restricted repertoire of activities or interests, including repetitive or stereotyped movements—hand flapping, spinning—and preoccupation with specific movements in objects.

Three out of four children with autism also have mental retardation. One in three children with autism will have, or will develop, seizure disorders. Many others may have co-occurring disorders such as allergies, or hearing or visual impairments. Self-injury behaviors may emerge.

Diagnoses among the spectrum of autism disorders include high functioning autism (Asperger syndrome), classical autism (also called Autistic Disorder, Kanner's Syndrome), Childhood Disintegrative Disorder (also called Heller's Disorder), or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Childhood Disintegrative Disorder (Heller's Disorder)

This rare diagnosis refers to a child having normal development who suddenly regresses, or fails to meet developmental milestones, at around age two. It is difficult to ascertain if this is an independent condition, since a pattern of normal development and later regression is often identified in autism spectrum disorders. (See the classifications of Dr. Judith Miles, page 21.)

Asperger syndrome High-functioning Autism

The difference between Asperger's and high functioning autism is ... the way they are spelled.

**—Tony Attwood, in
*Asperger's Syndrome:
A Guide for Parents and
Professionals.***

Asperger syndrome (AS) or Asperger Disorder [DSM-IV] represents a constellation of symptoms or characteristics at the “higher-functioning” end of the autism spectrum of pervasive developmental disorders, which is medically diagnosed by the presence of the majority of following traits:

- Unusual responses to stimulation and environment. A person with AS may be extremely sensitive to noise, smell or taste, and will respond to sensory overload with a meltdown or withdrawal.
- Limited interests or unusual preoccupations. People with high functioning autism tend to specialize on whatever they find interesting; they tend to “spout off” information.
- Repetitive routines or rituals. For a person with AS, ritual and routines provide comfort and predictability in a world that threatens his or her sense of control. If the routine is broken, typically, the person with high functioning autism may respond by having a meltdown.
- Speech and language peculiarities, such as tics or repetitive words or phrases.
- Uncoordinated or repetitive physical movements: walking on toes, flapping hands, fidgeting or facial tics.
- Impaired social and communication skills, such as the inability to “read” the facial expressions or body language of others; or the inability to intuit the rules (“give and take”) of conversation.
- Lack of flexibility. People with high functioning autism interpret life literally. They rely on a schedule and structure. Often they have a “Plan A” but not a “Plan B.”

A person with Asperger syndrome faces a new set of problems during adolescence, when peer pressure and “fitting in” take precedence over individuality. It can be difficult for people with high functioning autism to form relationships, often resulting in feelings of loneliness and frustration. It's not unusual for a person with AS to develop depression or anxiety. That being said, people with Asperger syndrome very often enjoy intimate relationships, and excel in their fields of interest.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is called a “subthreshold” condition. PDD-NOS is a diagnosis indicating that a child’s symptoms fall within the Autism Spectrum Disorder. For a PDD-NOS diagnosis, some—but not all—features of autism or another Pervasive Developmental Disorder must be identified.

Not all children with PDD-NOS have the same degree or intensity of the disorder: a child may show a few symptoms at school or in a neighborhood environment. Other children may exhibit more behaviors, and may have difficulties in all areas of their lives. (NICHY)

Information from the Yale Child Study Center web site notes:

While deficits in peer relations and unusual sensitivities are typically noted, social skills are less impaired than in classical autism. ... The limited available evidence suggest that children with PDD-NOS probably come to professional attention rather later than is the case with autistic children, and that intellectual deficits are less common.

Speech problems are common in young children, but often diminish as the child gets older. Often children have a monotone or robotic speech inflection.

Intelligence and cognitive abilities vary among individuals.

Emotional expression of some children may be “flat,” excessive or inappropriate to the situation, yet children with PDD-NOS can also express affection and humor.

Typical behaviors of children with PDD-NOS may include, to some degree:

- Resistance to change. Meltdowns are common when the routine is altered.
- Ritualistic or compulsive behaviors, such as “stimming.”
- Intense attachments and preoccupations. A child may be fascinated with light bulbs or a certain toy.
- Unusual responses to sensory experiences. Some kids may hate to be touched, but will enjoy roughhousing.
- Movement disorders such as hand flapping, rocking and swaying, or head rolling or banging.

NICHY:
**(National Dissemination
Center for Children with
Disabilities)**
[www.nichcy.org/pubs/
factshe/fs20txt.htm](http://www.nichcy.org/pubs/factshe/fs20txt.htm)

Rett syndrome

Rett syndrome is a pervasive developmental disorder that causes mental retardation and developmental degeneration. Inherited as an X-linked trait, it has been reported only in females.

Since the discovery of the MECP2 gene, [implicated in] Rett's, variants of the syndrome have been reported in males who have mutations of MECP2, with some overlap in the symptomatology observed in girls (Amir, et al, 1999; Schwartzman et al, 1999; Schanen et al, 1998). (Yale Child Study Center)

RESOURCE

International Rett Syndrome Association

9121 Piscataway Road

Clinton, MD 20735

1-800-818-RETT

www.rettsyndrome.org

Infants with this disorder appear to have normal growth and development for at least five months. Parents may notice excess levels of hand patting, waving, and involuntary movements of the fingers, wrists and arms; however, these signs are subtle and may go unnoticed. At five months, there is a slowing of normal development and a failure to reach developmental milestones on time. Additionally, parents note the following signs:

- size of the child's head does not grow as much as it should between the ages of 5 and 48 months;
- loss of previously learned, useful hand skills (such as reaching for and grasping an object), and the development of stereotyped hand movements, especially hand wringing;
- loss of socially engaging behaviors like smiles and eye contact (however, these behaviors may redevelop later);
- loss of coordinated walking or body movements.

Additionally, expressive and receptive language skills become impaired, and severe psychomotor retardation develops.

A lack of interest in social relationships, loss of expressive language and the development of "stereotypies" can cause this disorder to be confused with classic autism.

Neurological Disorders

Neurological disorders of the brain may co-occur with autism spectrum disorders (ASD). Often a child with autism will display ADD/ADHD behaviors. Anxiety and panic disorders (as well as headaches) are common responses to sensory overload, and may accompany ASD. Individuals with ASD may develop mood disorders such as depression and dysthymia (chronically irritated, slightly depressed mood).

Attention Deficit Disorder (ADD)

Hyperactivity Disorder (HD)

Attention Deficit/Hyperactivity Disorder (ADHD)

Attention deficit disorders are neurological brain disorders that make it difficult to sit still, stay focused, remember instructions, play quietly or get along with others. These are treated with a combination of behavioral modifications, classroom interventions, and/or medication. For diagnosis, a person must exhibit characteristics of ADD or ADHD in more than one setting—in both school and home, for instance.

A person diagnosed with **attention-deficit disorder** (ADD) fails to pay attention to details; has difficulty sustaining interest in tasks or play; will not follow through on instructions; procrastinates; is easily distracted; and is forgetful.

With **hyperactivity disorder**, a person typically fidgets or squirms; has difficulty playing quietly; often talks excessively; interrupts or intrudes on others, and displays a lack of ability to inhibit impulses.

Depression

Depression is characterized by a depressed or irritable mood most of the day, every day, for at least a year. In addition, a child will have sleep problems; will lose or gain weight; will feel restless; have fatigue or loss of energy; have feelings of worthlessness or excessive guilt; or have diminished ability to think or concentrate. Someone with depression may also have recurrent thoughts of death or suicide, or will make suicide attempts.

Depression is often accompanied by headaches (40% of females), general physical complaints or gastrointestinal problems.

Reference:

For a detailed discussion of childhood brain disorders, see “The ABCs of Children’s Mental Health” (2001) from Project LIFE.

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD) is characterized by anxious thoughts or rituals that cannot be controlled. People with OCD may be plagued by persistent, unwelcome thoughts or images, or by the urgent need to perform certain rituals such as hand-washing, checking, counting or ordering. Many of the behaviors associated with OCD are also typically seen in autism. Research studying the similarities between autism and OCD behaviors suggests a “similar biobehavioral model in place in both autism and obsessive-compulsive disorder.” (Winter and Schreibman)

Schizophrenia

While symptoms of schizophrenia usually appear in late adolescence, in rare cases childhood schizophrenia may be misdiagnosed as an autism disorder.

Schizophrenia is noted by:

- Hallucinations—usually visual or auditory, rarely olfactory
- Delusions—false beliefs, paranoia
- Disorganized speech, incoherence
- Disorganized or catatonic behavior
- Negative symptoms, specifically flat affect, lack of speech
- Marked impairment of at least six months duration

Tourette syndrome (TS)

Tourette Syndrome is an inherited neurological disorder characterized by repeated involuntary movements and uncontrollable vocal sounds, called tics. Symptoms of TS appear before the individual is 18 years old, often when the child enters school.

Like autism, Tourette syndrome (which occurs mainly in males) affects behavior, social interaction, movement and language. It is not a component of autism, but can be misdiagnosed as autism.

“Repetitive movements, stereotypies, [echolalia], self-injurious behaviors and compulsive behaviors are common in autistic spectrum, [as well as] a subset of severe TS without autism.” (Barnhill and Horrigan)

Both syndromes are thought to have complex genetic and environmental origins. Research “suggests a genetic relationship between autism and Tourette syndrome, as well as a genetic relationship of both with disorders of immune dysregulation.” (Becker et al.)

Glossary

ABA (Applied Behavior Analysis): Acronym used to refer to a family of techniques based on behavioral principles.

aphasia: Loss of ability to use or understand words.

atypical autism : A general term for conditions that are similar to (but don't quite fit) the set of criteria for a diagnosis of autism or related disorders. (See PDD-NOS)

Auditory Integration Training (AIT): A technique used to relieve hearing dysfunctions by “retraining” the ear to hear in a more balanced fashion. *Also used: Tomatis, Berard, Samonas training*

Augmentative and Alternative Communication (AAC): Any method of communicating that can supplement the ordinary methods of speech and handwriting, where these are impaired. AAC devices range from low-tech (“photo boards” and picture exchange communication) to “high tech” (augmentative speech device).

Autism Diagnostic Interview (ADI): A standardized, semi-structured parent interview that can be used to assess children and adults with a mental age of 18 months and up.

Autism Diagnostic Observation Schedule (ADOS): A standard, semi-structured play session that allows the examiner to observe communicative and social behaviors that are associated with autism.

autistic savant: A rare condition in which an individual with autism displays a brilliant talent or intelligence in a particular area, such as feats of memory, mathematics or music.

Central auditory processing disorder (CAPD): A hearing impairment located in the brain (where incoming speech is “processed” and understood), rather than in the ear.

Childhood Autism Rating Scale (CARS): A rating scale developed to diagnose autism, based on ratings in 15 areas.

chromosomes: Structures in the cell nucleus that bear an individual's genetic information.

Diagnostic and Statistical Manual IV (DSM-IV): The official system for classification of psychological and psychiatric disorders prepared by and published by the American Psychiatric Association.

discrete trial: A short, instructional training, which has three distinct parts: a direction, a behavior, and a consequence. Many discrete trial programs rely heavily on directions or commands as the signal to begin the discrete trial.

dyspraxia: Impaired or painful functioning in any organ.

echolalia: Repeating words or phrases heard previously. The echoing may occur immediately after hearing the word or phrase, or much later. **Delayed echolalia:** can occur days or weeks after hearing the word or phrase. **Functional echolalia:** using a quoted phrase in a way that has shared meaning, for example, a child who sings the Barney jingle to ask for a Barney videotape, or says "Get your shoes and socks" to ask to go outside.

electroencephalogram (EEG): A test that uses electrodes placed on the scalp to record electrical brain activity. It is often used to diagnose seizure disorders or to look for abnormal brain wave patterns.

Fragile X Syndrome: A genetic disorder that shares many of the characteristics of autism.

gene: Formed from DNA, genes are carried on the chromosomes and are responsible for the inherited characteristics that distinguish one individual from another.

hyperlexia: The ability to read at an early age, but not necessarily to understand what is being read. **hypo-:** inability to read.

hypotonia: low muscle tone.

Glossary

Individualized Educational Plan (IEP): A plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services. The IEP also identifies the methods by which the student's progress will be reviewed. For students 14 years or older, the IEP must include a plan for the transition to postsecondary education or the workplace, or a plan to help the student live as independently as possible in the community.

Landau-Kleffner Syndrome: Also known as acquired aphasia with convulsive disorder, it is characterized by a progressive loss of the ability to understand language and to use speech, following a period of normal speech development. It is accompanied by seizure activity and is typically diagnosed through a sleep EEG.

macrocephaly: A head circumference two standard deviations above average.

mainstreaming: Placement of a child with a disability in a regular classroom.

microcephaly: A head circumference two standard deviations below average, producing an abnormally small head and small brain.

occupational therapy (OT): Provided by an occupational therapist, OT aids in development of the fine motor skills used in daily living. Occupational therapy can focus on sensory issues (e.g., coordination of movement, balance) and on self-help skills such as dressing, using a fork and spoon, or grooming. OT also can address problems with visual perception and hand-eye coordination.

perseveration: Repetitive movement or speech, or obsessing on one idea or task.

Positron Emission Tomography (PET) Scan: A scanning device that uses low-dose radioactive sugar to measure brain activity.

prosopagnosia: brain-based inability to recognize faces.

psychomotor: Relating to motor action directly proceeding from mental activity.

sensorimotor: Pertaining to brain activity other than automatic functions (respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement, and relates to senses (sight, smell, touch and hearing).

sensory integration (SI): A term applied to the way the brain processes sensory stimulation or sensation from the body, and then translates that information into specific, planned, coordinated motor activity.

serotonin: A chemical neurotransmitter that regulates mood, as well as the physiological processes of sleep, pain and sensory perception, motor function, appetite, learning and memory.

Speech-Language Pathologist: Specialist in the area of human communication. The focus of language therapy is to increase a person's ability to understand and interact with their environment.

stereotypes: Excessive repetition (or lack of variation) in movements, ideas, or patterns of speech, especially when viewed as a symptom of certain developmental disorders.

stim: (“stimming”): Short for “self-stimulation,” a term for behaviors whose sole purpose appears to be to stimulate one's own senses. An example is hand-flapping. Many people with autism report that some “self-stims” may serve a regulatory function, such as calming, adding concentration, or shutting out an overwhelming sound.

TEACCH (Treatment and Education of Autism and related Communication handicapped Children): TEACCH methodology is a collection of techniques including highly structured classrooms and visual supports. This approach may be used to enhance receptive communication and sequential memory.

Theory of Mind: The ability to understand that others have beliefs, desires, emotions and intentions that are different from one's own, and to interpret these through a process of inferring subtle verbal or nonverbal cues.

tic: An involuntary facial expression (constant winking, for instance) or vocalization (grunting, repeating words or sounds).

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Resources

ADA (Americans with Disabilities Act) www.usdoj.gov/crt/ada/adahom1.htm

For information and technical assistance, call (800) 514-0301.

Autism Network International (ANI) <http://ani.autistics.org> “An autistic-run self-help and advocacy organization for autistic people.”

Autism Research Institute (ARI) www.autismresearchinstitute.com Fax (619)563-6840; contact for Defeat Autism Now physicians.

Autism Society of America www.autism-society.org

Central Missouri Chapter (660) 429-6409; Western Missouri Chapter (816) 353-7560

American Speech-Language-Hearing Association www.asha.org 1-800-638-8255

Cure Autism Now! www.cureautismnow.org 1-888-828-8476; (323) 549-0500

First Steps www.dese.state.mo.us/divspeced/FirstSteps/index.html. This Missouri state program provides services for children (birth to age 3) who have delayed development or diagnosed conditions associated with development disabilities. 1-866-583-2392

Governor’s Council on Disability www.gcd.oa.mo.gov 1-800-877-8249

Judevine Centers. St. Louis (314)432-6200; Columbia 1-800-675-4241

Southeast MO (573)339-9300; Southwest MO 1-800-420-7410

MedLine www.nlm.nih.gov/medlineplus/autism.html National Library of Medicine information and news on autism.

Missouri Autism Consultants (MACs) 1-866-481-3841

On-site consultation to Missouri school districts, for programs for students with autism.

Missouri Department of Mental Health www.dmh.missouri.gov

Toll-free 1-800-364-9687.

Missouri Developmental Disabilities Resource Center www.moddrc.com

Locate needed services and obtain materials related to developmental disabilities and low incidence disabilities. MODDRC services are available free to Missourians. 1-800-444-0821

Missouri Families for Effective Autism Treatment (MO-FEAT) (314)645-6877

www.MO-FEAT.org Advocacy and information.

Missouri Family Trust www.missourifamilytrust.org 1-888-671-1069

The Missouri Family Trust administers a master trust which manages individual special needs trusts for persons with a mental or physical disability.

MU Autism Clinic (573)884-1871; 882-6991

National Alliance for Autism Research www.naar.org/naar.asp

National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. www.cdc.gov/ncbddd/dd/ddautism.htm

National Institute of Child Health & Human Development. www.nichd.nih.gov/autism
1-800-370-2943

National Institute on Deafness and Other Communication Disorders Information Clearinghouse www.nidcd.nih.gov 1-800-241-1044; 800-241-1055 (TTD/TTY)

National Institute of Mental Health (NIMH) www.nimh.nih.gov 1-866-615-6464

National Institute of Neurological Disorders and Stroke (NINDS)
www.ninds.nih.gov 1-800-352-9424

Online Asperger Syndrome Information and Support (OASIS)
www.aspergersyndrome.org

Project ACCESS www.smsu.edu/access 1-866-481-3841

This project trains professionals who serve children with autism and pervasive developmental disorders. Contact Joanie Armstrong at (417)836-6396.

Project LIFE. www.missouri.edu/~projlife 1-800-392-7348

Project LIFE offers publications, training and consultation on mental health topics, free of charge to Missourians.

Society for Neuroscience www.sfn.org (202) 462-6688 Information and fact sheets available on-line.

Talk Autism. www.talkautism.org

Resource for the autism community to share knowledge, information and assistance.

Yale University Child Study Center <http://info.med.yale.edu/chldstdy/autism/index.html>
Information about pervasive developmental disorders.

NOTES

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